

Dracup, Kathleen 2009

Dr. Kathleen Dracup Oral History 2009

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NINR History Project

Telephone Interview with Dr. Kathleen Dracup Conducted on September 2, 2009, by Philip Cantelon

PC: I'm speaking with Kathleen Dracup on September 2nd, 2009. May I have your permission to record the call?

KD: Absolutely.

PC: And use the material in the book?

KD: Yes.

PC: Thank you. What I'd like to start out is a brief rundown of some of the more recent grants you've received from NINR.

KD: More recently I have received two grants from NINR. One is to look at preparing family members for an emergency at home, which could either be a cardiac or respiratory emergency. I had received funding from NHLBI to do that particular study with adults where one of the adults had a heart condition that put them at risk for a cardiac arrest, and in conducting that study, we realized that many of the same issues exist when infants are born, often prematurely or with an anatomical problem that would put them at risk. And so we then looked at the ways that nurses prepare parents to respond to what usually in an infant is a respiratory arrest, but it could be a cardiac arrest, how they're trained at the hospital, and if that training increases anxiety and depression and stress or if there's a way to teach them that reduces the negative psychological consequences. And so we conducted that study and looked at different methods of teaching, finding that in fact a method that combined video, which standardized the teaching, plus a support group was actually the most helpful. Information was retained the longest and with the fewest psychological consequences. So that's one study.

A second study that I've just completed is a study looking at whether or not we can instruct patients who are already identified as having heart disease and about what to do when they have heart attack symptoms. It's a problem in the United States that continues to beset emergency rooms and cardiology as a field. We have now wonderful treatments, but they're time dependent. For every thirty minutes that a person waits with heart attack symptoms before coming to the emergency room for care, there's an increase in annual mortality of seven percent. So we're very concerned about the heart muscle dying during a heart attack because the patient just hasn't come to the hospital and started getting the treatments that would reverse the process. So we randomized 3500 patients into an experimental group that received instruction about the need to get to the hospital quickly and what the rewards were as well as instruction about what the heart attack symptoms were, what the nature of the heart attack symptoms might be. And then we compared them to a control group and found, much to our dismay and surprise, that there was absolutely no difference in a two-year follow-up between patients who had received all of our instructions compared to patients who had not received instructions. They both delayed approximately two hours median time. So those are the two studies that NINR most recently funded.

PC: I hope that doesn't speak to emergency rooms more than the people.

KD: No. We only measured from the time of symptom onset till their arrival at the emergency room. Actually emergency rooms have gotten very good at this. It used to be hours people would be delayed inside the hospital, but because it's a measure for hospital accreditation now—how quickly people get from admission to definitive treatment—hospitals have gotten incredibly organized around this. And so the number one cause of delay is the patient, and it's really that the patient doesn't identify the symptoms as cardiac or delays in other ways—tries to call the doctor, doctor's office, self treat, does things that just contribute to them staying where they are. So we did discover a lot of things that were very useful in this study, and we've had about ten papers that are either published or in press. We discovered many things about what patients know and don't know, and we are preparing another study for submission hoping to have a better outcome than we had in this trial.

Phil, I've got one more study that is just currently in process now where we're randomizing patients who have heart failure. These are people who have already had heart attacks or bypass surgery, some diagnosed heart disease, and now they've moved along in their illness and they have symptoms of heart failure—difficulty breathing and abnormal tiredness, difficulty with appetite, exercise restrictions. We targeted patients who live in rural areas who don't have access to a lot of the kinds of medical and nursing support that heart failure patients who live closer to a university setting might. So we're again helping people, we hope, to stay out of the hospital, so our end points are actually rehospitalization and death for cardiac reasons. We are instructing them and following them up in one of two experimental groups and then comparing those to a control group. So that's the latest study that NINR is doing. Obviously all of my research has been in the area of cardiology, and it's all about disease management, preparation of patients and their families to act appropriately when they don't have any guidance from the medical system.

PC: What would you say has been the impact of NINR on nursing research in the thirty-so years that you've been involved, well twenty-five I guess for NINR?

KD: NINR has certainly extended our knowledge about both the barriers to adherence and how those barriers can be minimized.

PC: Adherence to?

KD: Adherence to either preventative strategies—diet, exercise—and with very few exceptions, NINR is one of the few institutes who really is focused on health promotion as well as treating disease. NINR has really focused on, for instance, adherence of preventative behaviors, adherence to those when there isn't a disease to provide motivation. It's really how do you keep people healthier longer, and I think that some of the trials that have been conducted around the risk factors for non-adherence, how to strategize if you're a healthcare provider to involve family members, involve the patient in meaningful ways. A lot of the research that NINR has funded has been related to that, and then disease management. Particularly as we've moved into an older population, a lot of the research that NINR has funded over the years has been focused on disease management, which is that kind of broad umbrella category which covers symptom management, end-of-life issues, decisions around treatment options. For instance, one of the studies that I know NINR funded ended up in a book by a woman named Sharon Kaufman called *Dying in the ICU*. In her study that was NINR funded, Sharon participated for two years in family rounds, medical rounds, just spent two years in ICUs looking at the way end-of-life issues are discussed or not discussed and how decisions are made around withholding or withdrawing treatment. And so NINR has I think contributed more than any other institute to clarify the issues for the medical system around disease management and end-of-life care.

PC: Has it changed the nursing profession in any way?

KD: Well, of course it's so synergistic, it's hard to say. Clearly what happened, as you wrote about so beautifully in those early chapters, when NINR was initiated at NIH, nursing did not have a strong scientific tradition, it didn't have a lot of doctorally prepared scientists within its ranks, and it was hard to encourage people to do that because funding was difficult to get from the other institutes who weren't interested in the kinds of issues that nurses are often interested in which is around patient education and counseling, psychological outcomes, disease management. Those are issues that have become of greater interest to some of the other institutes but clearly weren't funded in the traditional NIH system. And so NINR has often been the catalyst for postdoctoral training, predoctoral training, for the first R01 that a nurse investigator gets, getting them started on an academic career. So I think it's made a huge difference in people's lives in terms of their ability to research the kind of issues that nurses are interested in as well as be successful academically.

PC: Have they managed to gain any more credibility at NIH?

KD: I think they have. It's hard—because I'm on the West Coast

PC: That's why I asked the question. I [inaudible] be too close.

KD: I'm not as involved in a lot of the day-to-day NIH that I think people who are very close and can be called on for ad hoc advisory panel, but I probably am at some NIH meeting four or five times a year, and over the years there has definitely been a difference. We've been really lucky with the directors that we've had in both Ada Sue Hinshaw and Patricia Grady, which are the two of course that I've known because they both had tremendous credibility on the NIH campus for different reasons. Ada Sue because of who she was. She was an outsider but she quickly gained credibility. And then Patricia because of her familiarity with NIH and other institutes and then her own research portfolio which is the kind of portfolio that NIH was very accustomed to. So I think that we've been really lucky in the leadership that we've had. And I think in general at the end of the day, budgets talk. So if you look at the institute compared to other institutes, I would say we're still struggling for our place. But NINR has been strategic in co-funding a number of grants so that they are involved with other institutes in the co-funding and then also with the science. So actually the last grant that I told you about I submitted to NHLBI and was funded by them, but NINR is providing some funding as a co-sponsor. And that's been something that Pat Grady has really emphasized as the director that she would work with other institutes in co-funding research that met the strategic priorities of the institute.

PC: How much do you think has—I guess you've sort of answered that question. What would you say were the great successes of NINR, the ones you mentioned or would you have any?

KD: What I'm thinking about is how difficult it is to have successes at NINR because of the nature of nursing research. As I said, what NINR has done is provided a place where scientists who are interested in issues around coping and stress and disease prevention and end-of-life care, those are priorities. But fortunately or unfortunately for society, those are not the really highly publicized hot *New York Times* science kinds of topics, and I think that that's a stumbling block for NINR if you will.

PC: In other words getting the word out?

KD: Well, getting the word out and, you know, it's not a new vaccine or it's not discovery of the AIDS virus. It's just the nature of research that is conducted by nurses or people who are interested in nursing phenomenon. It's the every day of patients' lives, no doubt about it. It's what makes people feel better or worse in their day if they have cancer or if they have some debilitating disease, but it's not hot. And so I think that that's been a problem. I think we've learned a lot about, for instance, pain management. NINR has had that as a priority. It's a terrible problem for people with all kinds of diseases, but particularly cancer, and we've learned a lot about how to manage pain, symptoms like lymphedema, and those are real contributions, but they're not contributions that will be on the front page of the *New York Times*, which I think is always a challenge for Pat because when she goes to Congress, that's what they're looking for. So I think absolutely the things that you cited in your chapters, the work, for instance, around transitions where Dottie Brooten's work about advanced practice nurses and their ability to provide care in the community that is cheaper and it keeps people out of the hospital. All of that is really I think important contributions to healthcare and the scientific evidence we have for what we do.

PC: What do you see as the trends for nursing research over the next let's say ten years?

KD: I think integration of technology will be a big trend. It's so hard to imagine that we didn't even have e-mail in the late eighties. Isn't that stunning?

PC: I got my first one in 1988.

KD: Oh, well you were an early adapter.

PC: I was because I was doing a book on a company that did all of its internal work by e-mail, but you couldn't connect with anybody else.

KD: Right. You were an island. I mean it's just stunning to think about where we've gone with handheld devices. I'm working with a student, for example, who's requesting NINR funding, and she's developed an intervention to support exercise in older sedentary women that is cellphone based. So I think the integration of technology in supporting behaviors that we now know, either through NINR or through other agencies, are the ones that keep people healthy and functional and out of the hospital. So exercise, of course obesity, a huge problem across all of the institutes, across all of the U.S. And so interventions for obesity that incorporate technology, I think that will be one very strong area. A second is biomarkers. We really need to identify which biomarkers are important indicators of progression of disease which are diagnostic of either symptoms or disease, and I think we'll see more and more integration of biomarkers into our research. I think another area that nursing has struggled with has been measuring the phenomenon that we're interested in. Much of what we think we know is important in doing our research is essentially gathered by self-report, and yet we know that that's very flawed. So how do we measure psychological states? For example, in my research I've discovered that anxiety is very predictive of thirty-day complication rates in the hospital in these cardiac patients. If they come in highly anxious, then that's very predictive with everything else held constant. But how do we measure anxiety? Many of these measurements have, as I've said, been self-reports so I think nursing scientists will be continuing to work on measuring the unobservable and making sure that our measurements are valid and reliable. I think end-of-life will continue to be just because of all the healthcare debate, thank you Sarah Palin. Yes, we will have to measure those death panels. So I think end-of-life care will continue to be a huge issue that will be much funded by NINR. So technology, instruments, biomarkers, end-of-life care, and then disease management, particularly in this American population who is older and obese. So I think that those will be the areas. And again, this is the problem, Phil, they're not sexy. How do you get a sixty-five-year-old obese person to exercise more? People have been asking that question for decades. So we just have to figure out will technology be the answer we haven't had in the past. Are there other things we should be measuring that we haven't been able to measure well that might be clues to how we could intervene in behavior?

PC: Or form obesity anonymous groups.

KD: Well, there are sort of that. Weight watchers actually has probably the best recidivism rates of any of them. They say it's definitely that social support.

PC: And changing habits.

KD: And changing habits.

PC: Behavioral patterns. What about cost effectiveness? It's come up with the new health plan.

KD: I think it's going to be across NIH. I don't think that NINR is going to be the messiah in this one. There's no institute that will look at, I think, a clinical trial that doesn't have a cost effectiveness analysis. It's just too hot in healthcare right now.

PC: Who are the groups that are going to be making policy decisions for the future for nursing research?

KD: I think all of the institutes call on the people who are creating the science. Whether that's one of the NIH institutes or IOM, I think the people who will be making those strategic decisions are the scientists. At least that's who I hope they are.

PC: More than the insurance companies or the—

KD: Yes. It can't be corporate America, it can't be lobbyists, and it really can't be bureaucrats. I know I'm on tape here, but that's why it can't be NIH because in general, those are people who might have done science at one point, but no longer do. They're supporting science, but they're not doing science. They don't necessarily know the latest literature, they don't know what are the key questions anymore. So it really can't be the full-time NIH staff, it can't be of course corporate America, and it can't be the politicians. It really does have to be the scientists.

PC: You said not the lobbyists. So does that include the professional nursing groups?

KD: The professional nursing groups would say that they represent those nurse scientists, but that they're just focused on a special aspect of nursing care. Let's take cancer for example. They would convene a group of nurse scientists who are interested in cancer, identify priorities, and then lobby for those priorities with NINR. On the one hand yes, that's okay because what's the difference if they meet in the cancer society building or in NIH? On the other hand, I think that there always is—they always talked about reading a translation is like kissing a woman through a veil, and I think that there's always the problem of a translation being removed one step, that the nursing society does put its own spin on things. So I don't see them as a lobbyist group the way I see . . . the ANA is a lobbyist group or the AMA. Absolutely. Those groups I would hope are not the ones who are dictating where our science should go. But specialty groups certainly have something valid to say.

PC: I asked you about successes. Did I ask you about failures at NINR?

KD: No, you didn't. I'm sorry you did now. Phil, I've only had a little experience in other institutes. About half of my funding comes from other institutes, and because of that then I serve on their scientific reviews. And I would say that NINR struggles because its area of research emphasis, if you look at the four that are set right now—health disparities, quality of life, promoting health, preventing disease, end-of-life research—those are very broad. There could be a hundred directions in each of those, and so I think NINR struggles with the fact that its scientific umbrella is so large, so that it's very rare to be able to get in the room scientists who are doing that science that they're reviewing.

Maybe it's a fantasy, but I think for other institutes it's not so rare. If you're in neuro where Pat was or if you're at NHLBI or you're at cancer, it's more likely that the research scientists who are reviewing the research will be truly experts doing the work themselves in the field that they're reviewing. And I think that's more of a challenge for NINR because, as I said, it just covers such a broad spectrum of science.

PC: Does that mean that worthy things might not get funded because people don't know enough about them or that they are funded because they don't know enough about them?

KD: Both. Absolutely.

PC: So it's a two-edged sword that cuts both ways and neither of them good necessarily.

KD: Yes, exactly. I just think that it's possible that someone who doesn't know the science might react to the research methodology in a negative way or in a very positive way, you know, of going on both sides really just out of ignorance, thinking that something is highly innovative when actually it's been done a great deal, or thinking that something is pedestrian when in fact this is cutting edge, this is the first time and that's why it seems sort of rudimentary. So I think it's hard when you have such a broad area of science.

PC: The phrase "cutting edge" is used probably more than it should be in nursing science, but can you give me an example of a cutting-edge nursing research program or project?

KD: I'm stumbling around the program versus project.

PC: Either. I'll work with either.

KD: Okay. Let me just give it a little thought if I can come up with an example. I think for instance the work that has been done by a woman named Katherine Lee, L-E-E, and I think almost all her funding has been from NINR. She's focused on sleep, so her early research was really about sleep patterns and what disturbs sleep, how sleep is restorative or not restorative, and what are the factors that affect sleep. And then as her research program matured, she looked at different populations. She's looked at people without any diseases but with sleep challenges, like truck drivers and shift workers, and then she moved into populations that you might guess would have disturbed sleep, like new mothers. And she's worked with cancer researchers, looking at the kinds of effects of cancer treatments on sleep and how those effects could be moderated to improve sleep. If sleep is really restorative, which we know it is, and people you would think with a disease would need it the most, or with a new important role change like a parent, you would think that sleep would be increasingly important, but it's often the first to be challenged. And I think that her research has been really, if you talk about cutting edge, it has really provided insight into what the problems are around sleep and what some interventions really work and don't work.

This is a good example actually of the sleep lobby. There are sleep labs all over the U.S., and because it's not paid for by insurance, it's a business, and you go in and you spend the night in the lab, and then they tell you that you have sleep apnea and you should wear a CPAP machine. I don't know if you've ever seen anyone with CPAP, but it's a pretty big mask that you wear at night that increases the oxygen level of what you get. This is a whole business. There's millions of dollars being made on these sleep labs and the treatments for sleep apnea and the CPAP and all of this, and Kathy's research really addresses that. Not that she prescribes CPAP, but she really is looking at what are the problems that lead to sleep dysfunction, what are the treatments that work and don't work. And so I would say that that kind of research program is very cutting edge. This is the problem I think NINR has. If Pat goes up to the Hill and says to Congress, "Through our research we have highlighted what the barriers to a good night's sleep are and what people can do to enhance sleep," [Laughs]

PC: You'd have to wake up the congressmen to tell them.

KD: Exactly. It affects us so much in our day, but it's not like discovering the AIDS virus. So that's an example that I think is kind of emblematic of everything.

PC: Very helpful. Anything I've missed?

KD: No. No, I think I've talked much too much.

PC: Actually I've enjoyed it very much and learned a good deal. The only thing that I found when I was in the hospital that kept me up were the nurses coming in to draw blood, or the technicians, at three in the morning, wondering why.

KD: That's one of the things that we're really looking at now is that hospitals are supposed to be, according to our gal Florence, these places of rest and restorative nature, you know, fresh air, good food, and of course we've created these monstrosities that don't let you sleep and don't let you see the outside and give you terrible food. I think again that is the purview of nursing is how to take care of people when they're sick, and we've got to figure out a better way to do it.

PC: Thanks very much. I trust we will talk again.

KD: Okay. All right.

PC: Thanks. Bye.

KD: Thanks, Phil. Bye.

[End of interview]